eternal: healthcare for girls and women with cerebral palsy across the life course

Participant Information Sheet
(for parents of participants under 16 years)

Background and description of the study

We are doing a research study at the University of Birmingham. We want to help improve access to healthcare in the UK for teenage girls and adult women who have cerebral palsy (CP). This includes sexual and reproductive healthcare.

We want to learn and understand:

1. what it is like for teenage girls growing older with CP
2. how do teenage girls feel about the healthcare practices and treatments they use
3. What do teenage girls know about their sexual and reproductive health, and what is needed to make sure you keep safe and well.

The aim of this research is to help nurses and midwives to understand better:

- How the effects of CP change as girls get older.
- What helps girls get good quality sexual and reproductive healthcare.
- What makes it hard for girls to get good quality sexual and reproductive healthcare.

We would like to talk to girls (aged 14-17) about their experiences of living as a girl with CP, and using different health care services.

Parental consent is required for teenage girls (ages 14-16) to take part in this study.

What to do to take part?
For enquiries about the study and participation please contact the *eternal team* (details below). Teenage girls with CP who want to take part in the *eternal* study must have written permission from a parent/guardian. Daughter and parent/guardian will need to complete and sign a consent form. This can be done electronically or by another person if it is easier.

Once consent is given your daughter will be invited to participate in an interview with Dr Sonali Shah, the project researcher. Most interviews will last for about 30-60 minutes. They can be longer or be done in stages. The interview will be quite informal so your daughter can talk about the topic in her own way. Interviews can be in different formats will be recorded and transcribed, depending on individual access needs. They can be face-to-face in a mutually convenient space, via email or Facebook messenger or Skype. Only the researchers and a professional transcriber will have access to the interview transcripts. Parents/guardian can join the interview if both parties (daughter and parent) agree. Participation in the project is voluntary.

How will we use information about your daughter?

We will need to use information from your daughter for this research project. This information will include:

- her initials
- name
- contact details

People will use this information to do the research or to check her records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see her name or contact details. Her data will have a code name instead.

We will keep all information about her safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your daughter took part in the study.

We want to share the results locally, nationally and internationally through journal papers, presentations and workshops with health practitioners, disabled communities and researchers. This is to inform future health policies and practices on how to make reproductive and sexual healthcare accessible for disabled women in general and women with CP in particular.

Some of the information will be used to produce online educational materials for nursing students and professionals about what is needed to provide good quality healthcare to girls and women with CP, and other lifelong conditions.

Any photographs you choose to use in the interview will not be used in the final materials.

The educational materials will include a 25 minute documentary film, based on interviews with the women and nurses. If you are interested in also being involved in the film, please tick the box on the consent form. In the summer term, we will make contact about the documentary film. All those involved will receive a second consent form.

What are your choices about how your daughter's information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- at **www.hra.nhs.uk/patientdataandresearch**
- our leaflet available from https://www.birmingham.ac.uk/schools/nursing/research/eternal-healthcare-for-girls-and-women-with-cerebral-palsy-across-the-life-course.aspx
- by asking one of the research team
- by sending an email to researchgovernance@contacts.bham.ac.uk, or
- by ringing us on 0121 4142900.

We want to share the results locally, nationally and internationally through journal papers, presentations and workshops with health practitioners, disabled communities and researchers. This is to inform future health policies and practices on how to make reproductive and sexual healthcare accessible for girls and women with CP, and other impairments.

Some of the information will be used to produce educational materials for nursing students and professionals about what is needed to provide good quality healthcare to girls and women with CP, and other lifelong conditions; and for girls and women with CP to learn more about how the impairment manifests over the life course and the importance of sexual and reproductive healthcare.

Your daughter's stories will only be used in the production of educational materials if you have given consent.

The educational materials will include a 25 minute documentary film, based on interviews with the women and nurses. If your daughter might be interested in also being involved in the film, please tick the box on the consent form. In the summer term, we will make contact about the documentary film. All those involved will receive a second consent form.

***Eternal* study team contact details**

The core members of the research team are based at the School of Nursing, University of Birmingham. They have significant experience carrying out research in relation to sensitive topics. Dr Sonali Shah is a research fellow and has conducted research around disability, human rights and access to services for fifteen years. Julie Taylor is a Professor of Child Protection and Director of Research at the University of Birmingham in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust. Dr Caroline Bradbury-Jones has research interests in health inequalities, reproductive health and gender based violence.

The project steering group includes experts within healthcare and rehabilitation, social science and disability studies, and includes adults with CP

For enquiries about the study and participation please contact

Dr Sonali Shah

email: s.shah.3@bham.ac.uk

Tel: 0121 4142900

If you would like to make a complaint or to raise a query about the conduct of the research team, please contact:

Professor Julie Taylor – Director of Research, School of Nursing
j.taylor.1@bham.ac.uk

You can also find more details about how your information is used at
www.hra.nhs.uk/patientdataandresearch

Thank you for taking the time to read this information sheet and for considering your daughter taking part.